

Victorian Comprehensive Cancer Centre:

Involving the public and consumers in cancer research

Facilitator Manual



About


Audience

‘Involving the public and consumers in cancer research’ is for people who are interested in learning more about how the public (including consumers) can be involved in cancer research. It will be of particular interest for those who are interested in getting involved in research, or involving others in research.

How to use this resource

This document includes a framework of learning areas and learning outcomes designed to support researchers to understand how the public can get involved in health research. This manual has been written so that no formal scientific training is required to use it or deliver training.

Share and share alike

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Some of the resources in this manual have been adapted from:

‘Building Research Partnerships’, created by Macmillan Cancer Support and available under the same licence.

More information about that resource can be found here:

macmillan.org.uk/researchlearning

Acknowledgements

This manual was created by Jack Nunn for the Victorian Comprehensive Cancer Centre (VCCC), 2016.

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[Jacknunn.com](https://jacknunn.com)

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About the session 'Involving the public and consumers in research'

Aim of the learning session:

To support participants to understand ways the public can be involved in research.

Outcomes

After attending, participants will be able to:

- Explain what public involvement in research is and why it is important
- Explain ways of involving people in research
- Explain the national and international context of involvement in research
- Explain how all of the above are relevant to the work of VCCC

Timings

This session is designed to run for 30 minutes.

Delivery

In order to achieve specific learning outcomes, this workshop will be delivered using a combination of:

- Pre-prepared learning resources
- Interactive activities
- Facilitated discussions

Learning resources

Some of the learning resources will be used during the session and some will be provided afterwards for additional information.

All the learning resources created for this session will be shared electronically with all participants after they have attended.

Session outline

Session One

Session	Summary	Time (min)
What is involvement in research?	An exploration of the terms and a discussion about what public involvement in research means.	3
Why involve the public?	An exploration of reasons to involve consumers, including examples of improved research and grant applications.	5
Who can be involved and how?	A discussion about examples of public involvement in research, looking at the whole research cycle.	12
Exploring the context	An exploration of the organisational, national and international context of consumer involvement in research.	3
Agreeing next steps	An opportunity for participants to commit to actions to involve consumers and describe and support needs they feel they have.	5
Closing	Closing remarks	2

Session Two

Session	Summary	Time (min)
Research Methods and terminology	How research is conducted and the terminology used	15
Appraising research		15

Detailed facilitation plan

Activities

Session One

Session	Summary	Learning aims	Learning outcomes	Activity instructions	Resources	Time
What is involvement in research?	An exploration of the terms and a discussion about what public involvement in research means.	To help define what is meant by the word 'involvement' in the context of research	Be able to explain the terms 'involvement' Be able to explain why we involve people	<p>Assess knowledge in the room:</p> <ul style="list-style-type: none"> Ask people what they understand by the terms 'involvement in research' Does anyone have an examples of it that they know? <p>Read out definition: The National Health and Medical Research Council defines involvement as: "research being carried out with or by consumers and community members rather than to, about or for them"</p> <p>State that detailed explanations are in the resources that will be shared. Mention briefly that the word 'consumer' is used in Australia but that you will use 'public'</p>	Resource 1: Definitions of 'involvement' in research	3

Session	Summary	Learning aims	Learning outcomes	Activity instructions	Resources	Time
Why involve the public?	An exploration of reasons to involve consumers, including examples of improved research and grant applications.	To explain the importance of public involvement in research	Be able to explain why public involvement in research is important and give examples	<ul style="list-style-type: none"> Ask people if they think involving the public in research is important. If not, why, if so, why? If attitudes vary, consider using 'Resource 5: Attitudes' and asking people to read out points and discuss if they agree or disagree <p>Give examples of where involvement has improved research:</p> <ul style="list-style-type: none"> It can help with developing grants and making grant applications¹ It can help identify and prioritise issues, avoiding wasting funds doing research that is not needed² It can help improve design of trials³ It can lead to better recruitment to trials⁴ Support the development of partnerships across clinical service delivery and research environment (VCCC is an example of this!) 	Resource 2: Why involve the public? How can it be done? Resource 5: Attitudes	5
Who can be involved and how?	A discussion about examples of public involvement in research, looking at the whole research cycle.	To explore the many ways the public can be involved in research	Be able to summarise the ways the public can be involved in research and give examples.	<ul style="list-style-type: none"> Ask people what 'the public' means and who this term excludes Ask people to put the stages of the research cycle in order Give examples of public involvement in research at each stage 	Resource 3: Stages of the research cycle	10

¹ <http://www.ncbi.nlm.nih.gov/pubmed/24118732>

² <http://www.sciencedirect.com/science/article/pii/S0140673613622291>

³ <http://www.sciencedirect.com/science/article/pii/S0168851009002929>

⁴ <http://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-015-0008-5>

Session	Summary	Learning aims	Learning outcomes	Activity instructions	Resources	Time
Exploring the context	An exploration of the organisational, national and international context of consumer involvement in research.	To examine variation in attitudes, terminology around involvement in research	Be able to explain different kinds of attitudes towards involvement around the world and describe where Victoria is within that context.	<ul style="list-style-type: none"> Ask people if they can name specific research organisations or research projects happening in Australia or Victoria? Ask if they can give examples of involvement for any of these. Summarise the international, Australian and Victorian context of involvement in research using 'Resource 4: Exploring the context' – ask what the word 'meaningful' involvement means. State that VCCC had a 'Consumer Strategic Advisory Group' at the start of the project and currently has 'VCCC Cancer Consumer Advisory Committee'. Ask what other ways the project could involve the public. 	Resource 4: Exploring the context All appropriate resources from 6-11	5
Agreeing next steps	An opportunity for participants to commit to actions to get involved as consumers and describe the support needs they feel they have.	To give an opportunity to make an action plan about next steps to support involvement in research	Participants will be able to state where to go next and who to contact if they want to either get involved or involve the public in research	<p>Ask participants to try and reflect on everything they have learned today or a resource they thought was really useful. In particular, what might be relevant to the work of VCCC?</p> <p>Ask them to consider the handout '6Rs', exploring roles, responsibilities etc.</p> <p>Hand people the action plans and read through it as a group, asking them to reflect on it. Ask if anyone would like to share their next action with the group. Offer people the option of sharing it.</p>	Resource 12: The 6Rs Resource 13: Action plan	5
Closing	Closing remarks			Summarise and close		2



Session Two

Session	Summary	Learning aims	Learning outcomes	Activity instructions	Resources	Time
Research Methods and terminology	How research is conducted and the terminology used	To introduce some of the language and methods of research and how the public can improve research	<ul style="list-style-type: none"> • Be able to explain the different methods of research used and the language used to describe it • Explain what critical appraisal is 	<p>Explain that there are a variety of research methods. Explain that the terminology is there to ensure everyone, both those doing the study as well as anyone enquiring about it, understands the process under which that particular research study is being undertaken (3 minutes).</p> <p>Distribute the 'Types of research' resource and the 'Blank definitions of research' resource and ask each group to choose a spokesperson and then to match the title with the description (you may want to produce cards that people can place on the terms).</p> <p>Leave the groups to work for about 5 minutes and give them a minute's warning before ending the session. Allow (5 minutes).</p> <p>Highlight that there are arrows on the sheet (one pointing to the future, the other to the past) and explain that this is a hint as to the direction of time for the type of research it is next to.</p> <p>Ask the groups to give their answers. Then use an example of each to ensure they understand the process named (use 'Definitions of research' resource for real life examples) (5 min)</p>	<p>Resource 14: Match the definitions to the letters</p> <p>Resource 15: Research Definitions</p> <p>Resource 16: Different types of research methods</p>	15

Session	Summary	Learning aims	Learning outcomes	Activity instructions	Resources	Time
Reviewing research documents and research appraisal	Research in the media, research appraisal and reviewing documents	Explore how our perceptions of research are affected by media coverage and to understand how research is appraised.	<ul style="list-style-type: none"> Explain how research is often portrayed in the media and the subsequent public opinion. Explain what critical appraisal is. 	<ul style="list-style-type: none"> Ask people to read Resource 17: 'LOMA Phase II clinical trial advert' or consider asking someone to read out the first page. Give people Resource 18: 'Participant Information Sheet – Phase II clinical trial' and ask them to read it in groups or pairs. Surprise the group by asking them what they think is good about it. Remind them the role of the public is to help make research better. Ask them if they would take LOMA. Do they have any questions about the research? Tell them they have just critically appraised research – give them 'Resource 9: Questions to ask about research'. 	Resource 17: 'LOMA Phase II clinical trial advert' Resource 18: 'Participant Information Sheet – Phase II clinical trial' Resource 9: Questions to ask about research	15

Resources Summary

Number	Title
1	Definitions of 'involvement' in research
2	Why involve the public? How can it be done?
3	Stages of the research cycle
4	Exploring the context
5	Attitudes
6	What are you doing to involve people?
7	Answering important questions using Maslow's 'hierarchy of needs'
8	Patient, consumer and public involvement
9	Questions to ask about research
10	Stories and facts about public involvement in research
11	Diagram of engagement, participation and involvement in research
12	The 6rs
13	Action plan
14	Match the definitions to the letters
15	Research Definitions
16	Different types of research methods
17	'LOMA Phase II clinical trial advert'
18	'Participant Information Sheet – Phase II clinical trial'

Resources

This section of the manual contains resources which can be used as worksheets or handed out as information to aid discussion.

Each resource is numbered and some are referenced in particular activities.

All the resources are licensed under Creative Commons which is a nonprofit organization that enables the sharing and use of creativity and knowledge through free legal tools.

If you are adapting something from this manual or creating something new for it we encourage you to find out more at <http://creativecommons.org/>.

Please note, if you have any resources you think would be good to include, or any ideas, suggestions or corrections, please email jack.nunn@gmail.com

Presenting, printing and using resources

All the resources in this manual have been designed so that they can be printed easily.

Printing is best done from the PDF version, although it is available in other formats such as Microsoft Word if you would like to edit or adapt materials.

Resource 1: Definitions of ‘public involvement’ in research

The National Health and Medical Research Council defines involvement as:

“research being carried out with or by consumers and community members rather than to, about or for them.”⁵

The Australian Commission on Safety and Quality in Health Care ‘Safety and Quality Improvement Guide Standard 2: Partnering with Consumers’ states that **‘patients and carers, in partnership with health service organisations and their healthcare providers’** should be involved in⁶:

- making decisions for service planning
- developing models of care
- measuring service and evaluating systems of care.

International definitions

The terms **‘involvement’**, **‘engagement’** and **‘participation’** have different meanings across the world and are sometimes used interchangeably.

Similarly, **‘stakeholders’**, **‘patient’**, **‘public’** and **‘citizen’** are used by many different organisations, often conveying different meanings. Australia uses a range of terms to describe involvement, including **‘consumer involvement’** or **‘community engagement’**, **‘involvement’** or **‘participation’**.

Internationally, other organisations describe involvement differently. INVOLVE, part of the UK’s National Institute for Health research describes it as **‘public involvement’**⁷. They state that public involvement in research as research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them. This includes, for example:

- working with research funders to prioritise research;
- offering advice as members of a project steering group;
- commenting on and developing research materials;
- undertaking interviews with research participants.

The Health Research Authority in England came up with a helpful description of **‘the public’**:

“When we use this term public means patients, potential patients or members of the public including those with known genetic dispositions, carers and people who use health and social care services as well as people from organisations that represent people who use health and social care services.”⁸

⁵ <https://consultations.nhmrc.gov.au/files/consultations/drafts/draftconsstatementconsultationversion140807.pdf>

⁶ http://web.archive.org/web/20160527051127/http://www.safetyandquality.gov.au/wp-content/uploads/2012/10/Standard2_Oct_2012_WEB.pdf

⁷ <http://web.archive.org/web/20160525045648/http://www.invo.org.uk/frequently-asked-questions/>

⁸ <http://www.hra.nhs.uk/documents/2013/10/hra-public-involvement-strategy-circulation-september-2013.pdf>

Resource 2: Why involve the public? How can it be done?

Involving the public in research can:

- Help with developing grants and making grant applications⁹
- Help identify and prioritise issues, avoiding wasting funds doing research that is not needed¹⁰
- Help improve design of trials¹¹
- Lead to better recruitment to trials¹²

Who is involved?

It is important to explore these different terms. Do you really need 'patient' involvement, or just someone to check something is in plain English – or do you need someone with a very specific experience or condition to help inform your work.

It is very important to reflect on the tasks that you will be asking people to do – and what skills, experience or knowledge that person might require. In addition, it's very important to always consider what support they might need. This might be learning and development, financial or emotional support – perhaps a buddy or mentor.

INVOLVE state:

'Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services'¹³.

⁹ <http://www.ncbi.nlm.nih.gov/pubmed/24118732>

¹⁰ <http://www.sciencedirect.com/science/article/pii/S0140673613622291>

¹¹ <http://www.sciencedirect.com/science/article/pii/S0168851009002929>

¹² <http://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-015-0008-5>

¹³ <http://web.archive.org/web/20160527051935/http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>

Which stage of the research cycle?

The public can be involved at every stage of the research cycle, from identifying topics, prioritisation, to funding, designing trials (improving recruitment), analysing data, dissemination and even translation.

Stage	Why involve the public	How	Example
Identifying and prioritising	Involving the public in helping to identify and prioritise research allows them to influence what will be researched and lets researchers check that research priorities are the same as those of people who have the conditions being researched or who use relevant services.	<p>Use a mixture of face to face and online tools to facilitate discussions with existing reference groups and networks.</p> <p>This can include inviting the public to an event or researchers attending public and patient forums and events.</p>	<ul style="list-style-type: none"> In Australia, a Consumer Research Forum was held by Cancer Voices for members from around Australia. They used the 'global café' technique so that all 40 participants could discuss and log their priorities on five major cancer research topic areas. The outcome of this exercise has been used by Cancer Voices to alert researchers and funders to consumer priorities¹⁴. A peer reviewed paper was produced to inform other interested cancer research funders about what people affected by cancer would like to see researched¹⁵. In the UK the James Lind Alliance facilitates Priority Setting Partnerships. These partnerships bring patients, carers and clinicians together to identify and prioritise the treatment uncertainties which they agree are the most important for research.
Funding or commissioning	Many funding organisations now involve members of the public in commissioning research. This gives a broader perspective to the review process, by considering the issues that	<ul style="list-style-type: none"> Involve members of the public in reviewing research proposals 	<ul style="list-style-type: none"> Applications for Cancer Council NSW Project Grant funding are first reviewed through the National Health and Medical Research Council (NHMRC) peer review process and then by the Consumer Review

¹⁴ <http://web.archive.org/web/20160603024117/http://cancerforum.org.au/letter-to-the-editor/2015/november/cancer-consumer-involvement-in-research-in-australia/>

¹⁵ <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3532819/>

Stage	Why involve the public	How	Example
	are important from a public perspective.	<ul style="list-style-type: none"> • Have a members of the public on research commissioning panels or boards • Research grant applications • Organisations representing groups or conditions commissioning research. 	<p>Panel. The Consumer Review Panel assesses the remaining fundable applications based on specially designed consumer criteria</p> <ul style="list-style-type: none"> • After asking people affected by multiple sclerosis, the MS Society decided to fund research into improving the day-to-day lives of the people it affects, as well as biomedical research. • A number of cancer research funding agencies, including Cancer Council NSW, Cancer Australia and others require researchers to describe in their research proposals the extent to which consumers are involved in their research. <p>Specifically, the requirement for consumer involvement in research may include the need to:</p> <ul style="list-style-type: none"> ○ Discuss the extent to which relevant informed consumers have been involved during the development of a research proposal; and ○ Provide evidence within the proposal for ongoing consumer involvement in the proposed research.¹⁶

¹⁶ <http://web.archive.org/web/20160525073652/http://sydney.edu.au/cancer-research/resources/consumer.php>

Stage	Why involve the public	How	Example
Designing and managing	Involving members of the public in the design of research helps to ensure that the research is relevant to the needs of people, helps ensure the research question and outcomes are clear and ensures the research method has thought about the needs of anybody participating in the research.	Involve the public in: <ul style="list-style-type: none"> • Reviewing proposals and commenting on any potential difficulties in the design • Developing research tools, information such as questionnaires, patient information sheets and consent forms • Monitoring and managing the research process • The selection process of staff and researchers 	<ul style="list-style-type: none"> • The 'Workplace Impact of Supported Employment Study' involved service users in the design of study through a local group. The purpose was to investigate the impact of Individual Placement and Support in a mental health catchment area. • Biobanking – Having members of the public and donors involved at every level, including a 'lay steering committee....who are themselves donors' results in 'a proportion of the participants being engaged in dynamic consent' which is more practical. 17
Undertaking	Involving members of the public in undertaking research can mean that research is carried out by people with a personal experience of the area of research or with relevant knowledge of a particular culture.	Involve the public in: <ul style="list-style-type: none"> • Gathering and reviewing documentary evidence • Carrying out interviews and running focus groups • Developing research tools and information • Analysing and interpreting the data or results of research. 	<ul style="list-style-type: none"> • The Macmillan Listening Study trained people affected by cancer to carry out research to identify the cancer research priorities of people affected by cancer • Research Buddies - there are many variations on this, but essentially it is having members of the public, often people affected by a condition, paired with researchers helping motivate and enthuse them about their work. WEHI's system is leading edge work in Australia, supported by a Consumer Advisory Panel at WEHI

¹⁷ <http://www.researchinvolvement.com/content/1/1/3>

Thank you to Bec Hanley for her assistance in compiling this list

Stage	Why involve the public	How	Example
Analysing and interpreting	Why: Publishing linked data and results in the public domain allows others to analyse any findings and facilitates a range of people to give their time, scrutiny and perspective to the research	Involve the public in: <ul style="list-style-type: none"> Interpreting and commenting on results Analysing publicly available open data 	<ul style="list-style-type: none"> The University Of Western Australia founded a programme to support researchers, consumers and the community to work in partnership to make decisions about research development using linked data. Genes in space, Eyewire, Cell slider and Foldit all allow the public to access data and interpret it.
Disseminating	Why: Dissemination is critical is the knowledge gained from the research is to have an impact. Good dissemination can also help identify the need for further research in a particular area.	Involve the public in: <ul style="list-style-type: none"> Developing the dissemination plan Summarising the research findings in clear and accessible ways Presenting at conferences, speaking to patients, support groups and service providers Publication in open access peer-reviewed scientific journals Publishing on websites, writing to journalists, creating leaflets for waiting rooms or community centres. 	The Eve Appeal sent a letter to everyone who took part in the UKCTOCS screening trial and offered them the chance to continue to receive updates.
Implementing	Why: Members of the public involved in research are often passionate to ensure that action happens as a result of the research and are often able to establish relationships with key agencies and policy makers.	Work in partnership to plan the implementation as early as possible.	Example: Service user researchers and a nursing researcher co-delivered training in therapeutic interventions to staff teams in a mental health trust (St George's, University of London)

Stage	Why involve the public	How	Example
Evaluating impact	By evaluating the impact of research and public involvement in research, you can help to build an evidence base and let others know about what worked well and what could be improved.	Involve the public in: <ul style="list-style-type: none"> • How you are going to monitor and evaluate the impact of the research, and the public involvement in the research! • Writing up (and publishing) an evaluation of the public involvement itself! 	The UK Clinical Research Collaboration published a report of a project to evaluate patient and public involvement in research.

This table is adapted from the resource ‘Building Research Partnerships’ – which can be downloaded for free here:

macmillan.org.uk/researchlearning

In addition, INVOLVE have a page of more resources which describe how you can involve people at each stage of the research cycle:

<http://www.invo.org.uk/posttypresource/where-and-how-to-involve-in-the-research-cycle/>

Resource 3: Stages of the research cycle

The next pages contain stages of the research cycle which can be printed off and handed out to participants so they can attempt to put them in the correct order.

Identify topics

Prioritise topics

Commission or fund proposals

Design research

Manage research

Collect data

Analyse and interpret data

Disseminate

Implement or translate findings

Evaluate impact

Resource 4: Exploring the context

Australian context

The National Health and Medical Research Council “Revised Statement on Consumer and Community Involvement in Health and Medical Research statement” says:

“Active involvement of consumers and community members in health and medical research benefits the quality and direction of research. The vision for the Statement is: Consumers, community members and researchers will work in partnerships based on understanding, respect and shared commitment to research that will improve the health of all Australians. Consumer and community involvement is about research being carried out with or by consumers and community members rather than to, about or for them. It includes consumers and community members working with research funders to prioritise research, being involved in grant funding processes and providing advice as members of project steering groups. This is distinct from people who are the participants in research projects”¹⁸

A recent review of public involvement by the National Institute for Health Research recommends that ‘relevance’ be one of the three measures of success of future public involvement in health and social care research.¹⁹

Relevance is defined as ‘**questions that reflect the interests and needs of patients, carers and clinicians**’²⁰

Cancer specific involvement

The ‘National Framework for Consumer Involvement in Cancer Control’ states:

‘The evidence is that where consumers are viewed as equal and integral members of health services, cancer research groups and policy development, there will be improved outcomes and experiences for those affected by cancer. In addition, **meaningful** consumer engagement can build a trusted and confident health service.’²¹

The Cancer Research Network at the University of Sydney state that:

‘consumer involvement in research is a rather loose term to describe the **participation or contribution of informed community members in the design, implementation, awareness raising and/or governance of research.** It varies markedly from involvement as research subjects and as passive recipients of information about research findings, such as that provided in the media.

An informed consumer is generally a member of an organised group who voices the consumer perspective and takes part in the decision-making process on behalf of consumers. Consumer representatives are usually nominated by a consumer organisation and are accountable to that organisation.

¹⁸ <http://consultations.nhmrc.gov.au/files/consultations/drafts/draftconsstatementconsultationversion140807.pdf>

¹⁹ <http://www.nihr.ac.uk/get-involved/Extra%20Mile2.pdf>

²⁰ <http://www.researchinvolvement.com/content/1/1/2>

²¹ http://web.archive.org/web/20160607052845/https://canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf

The nature and extent of consumer involvement will be dependent on the nature of the research project.

Cancer Australia created a 'National Framework for Consumer Involvement' which outlines the 'Core Principles of Consumer Engagement in Cancer Control'. It states:

These principles aim to guide and strengthen consumer engagement in all aspects of cancer care and control and place the needs of people most affected at the centre of all policy planning, service delivery, research, information and support.

Australia & New Zealand Breast Cancer Trials Group

The Australia & New Zealand Breast Cancer Trials Group (ANZ BCTG) is the first collaborative cancer clinical trials group in Australia to establish a consumer advisory panel.

The role of the ANZ BCTG CAP is to:

- provide a consumer perspective on relevant issues about clinical trials including recruitment, patient information for informed consent, new trial protocols and ethical issues;
- improve recruitment to breast cancer clinical trials;
- advocate for women who are participating in clinical trials;
- raise community awareness of breast cancer clinical trials and research; and
- represent consumer views on behalf of the ANZ BCTG to media, Government, community, consumer and research funding forums.

CAP members review and provide comment on clinical trial protocols and particularly patient information and consent documentation. All members of the ANZBCTG CAP have had a personal diagnosis of breast cancer. It is this experience which helps us provide an important perspective to ANZBCTG research programs as well as help improve clarity and identify potential issues for the researchers to consider²².

International context

A report from the National Institute for Health Research stated:

"public involvement in research has had a variety of impacts, including impact on the research (at all stages and levels), on the members of the public who were involved, on the researchers, on participants, on community organisations and the wider community. It has also influenced whether the results of research have been used to bring about change."²³

Victorian context

The following are examples of research projects or organisations in the state of Victoria with examples of public involvement:

Cancer 2015

Funded by the Victorian Cancer Agency, Cancer 2015 is a large-scale population-based cohort aiming to recruit 10,000 patients over five years to produce a high-resolution map of cancer patterns, survival outcomes and health economic metrics in Victoria, to produce an evidence base for

²² http://web.archive.org/web/20160607052049/https://consumerlearning.canceraustralia.gov.au/leonie_young
²³ http://www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf

affordable health care in the new genomic era. The project has a Reference Group with one consumer member to help guide the project.

Melbourne Genomics Health Alliance

Melbourne Genomics Health Alliance brings together the clinical, research and teaching strengths among Victoria's leading hospitals and research organisations, with a vision to deliver genomic medicine into everyday healthcare. The Melbourne Genomics Health Alliance is 'committed to including patient and community views in our work' and established Community Advisory Group in January 2014²⁴.

The Community Advisory Group provides advice, direction and advocacy on matters of policy, design and evaluation of Melbourne Genomics. The Community Advisory Group:

- advises the Executive Management Committee and Program Team on patient and community views so they are recognised and reflected in planning and policy development
- makes recommendations on project design and evaluation to ensure inclusion of patient perspectives
- identifies and advises the Executive Management Committee on patient and community engagement
- advocates on behalf of the community for equity of access to genomic testing and information

Walter and Eliza Hall

The Walter and Eliza Hall Institute of Medical Research is Australia's oldest medical research institute. The institute hosts more than 750 researchers who work to understand, prevent and treat diseases. They have a Consumer Advisory Panel in order to 'better connect our research with community experiences of disease and consumer expectations'. They also host an innovative consumer researcher buddy system, which guides the longitudinal involvement of consumers in grant and project development and two-way discussions between researchers and consumers.²⁵

Academic context

A recent paper about involvement concluded that best-practice is to "Involve early - Patient input is often most impactful in the project formation phase. Researchers tend to have a focus on scientific questions and less on the wider context of disease. Patients can bring the perspective of what it is like to live with a disease, or several diseases/comorbidities...By having patient organisations, and their patients, as funded partners, a patient perspective was incorporated into even the earliest drafts of the project proposal and work plan"²⁶

²⁴ <http://web.archive.org/web/20160525073041/http://www.melbournegenomics.org/about-us/community-involvement>

²⁵ <http://web.archive.org/web/20160525080652/http://www.wehi.edu.au/research-research-fields/clinical-translation/consumer-advisory-panel>

²⁶ <http://www.researchinvolvement.com/content/1/1/5>

Resource 5: Attitudes

Sometimes a change in attitude involves individuals reflecting on assumptions and actively challenging these. Here are some helpful quotations that sum up some attitudes, taken from papers recently published in the new journal 'Research Involvement and Engagement':

- "There is a perception that patients either will not understand or would not be interested in the day-to-day operations of a research project. This often means that patients are given simplified and inaccurate explanations of how a project is progressing, what the challenges are and what the results mean. In reality, the more patients are involved in the day-to-day activities of the project, and the more they are informed about its progress, the more they can understand, contribute and positively impact."²⁷
- Academic culture can often be very different from that of other spheres of work, and bringing lay representatives into the research arena helps to raise awareness of issues outside the academic culture box. This is particularly useful where researchers have moved through first and second degrees into doctorates and post-doctoral research in basic science. Lay members are more focussed on the practical aspects and outcomes of research and how it can affect patients and carers."²⁸
- "The idea of patient involvement can be difficult for researchers as it does not adhere to the traditional "scientific method". The experiential knowledge of patients and the public, according to some, lacks the objectivity, verifiability, universality and rationality of scientific knowledge. However, it is now increasingly appreciated among researchers that patients' knowledge and experience is valuable for research and contributes to increasing the quality, relevance and appropriateness of research processes"²⁹
- "A key feature of our model is that all research projects running through our facility are receiving involvement from a wide range of lay members. Individual lay members may get involved at a deeper level in specific projects, but they have broad involvement in everything that we do which means that on a monthly basis, there is always an opportunity for researchers and lay members to share opinions and ideas. This differs from many PPI models where individual projects are allocated one or two lay members whose involvement may go through peaks and troughs."³⁰
- "Actually, it's surprising that it has taken us this long to focus on patient engagement because the results we have thus far are nothing short of astounding. If patient engagement were a drug, it would be the blockbuster drug of the century and malpractice not to use it." *Leonard Kish—Principal and Co-Founder of VivaPhi*³¹

²⁷ <http://www.researchinvolvement.com/content/1/1/5>

²⁸ <http://www.researchinvolvement.com/content/pdf/s40900-015-0002-y.pdf>

²⁹ <http://www.researchinvolvement.com/content/1/1/4>

³⁰ <http://www.researchinvolvement.com/content/1/1/3>

³¹ <http://www.researchinvolvement.com/content/1/1/4>

Resource 6: What are you doing to involve people?

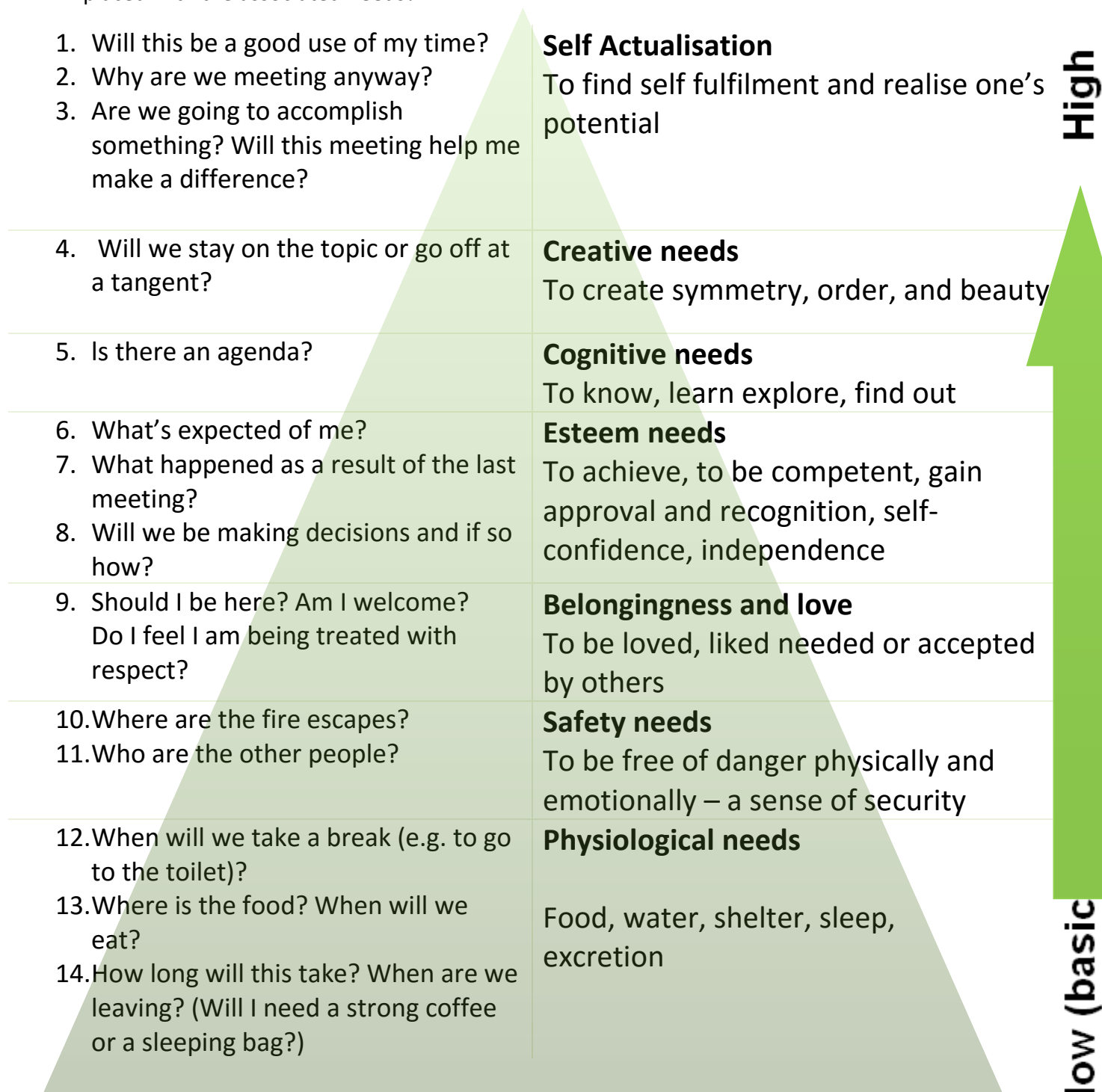
How are the public involved in your work? This is an action-based approach to the spectrum of involvement, designed to aid discussion about **assessing current involvement and planning for future activities**. The pyramid gives an indication of how many people might be involved in each action.

Actions	Involve people by...
Innovating This includes prototyping, piloting, establishing and creating new ways of doing things. This can include anything from building partnerships or buildings.	Supporting them to: <ul style="list-style-type: none"> • Design and carry out research • Create solutions • Implement ideas • Learn from actions
Managing, delivering and evaluating Working in partnership to manage ongoing activities.	Having: <ul style="list-style-type: none"> • Clear roles and tasks for the public • Elections and interviews when appropriate • Clear and accessible accountabilities for all roles (including staff), groups and committees. Asking them to take actions such as: <ul style="list-style-type: none"> • Managing or overseeing actions, processes and procurement • Directly delivering services or reviewing providers • Evaluating actions, processes and outcomes
Prioritising and planning Working in partnership to prioritise actions and plan implementation.	<ul style="list-style-type: none"> • Agreeing priorities in a clear, transparent way (this can include stopping certain actions) • Having clear accountabilities for planning at all stages • Having a transparent and adaptable budget
Listening, responding and acting Actively seeking feedback, responding to ideas, compliments and complaints with actions.	Asking them to help: <ul style="list-style-type: none"> • Interpret feedback • Influence responses to ideas, compliments and complaints • Asking for ideas for actions <p>This includes telling people what this action was, particularly those who have given feedback.</p>
Asking and discussing Asking people what they think, need and want and discussing it with them.	Inviting people from your intended audience or people you are trying to help to: <ul style="list-style-type: none"> • Design how you will collect feedback and interpret the results • Identify any potential barriers that might stop people from giving feedback.
Telling Giving information about what you have done, are doing or are going to do.	<ul style="list-style-type: none"> • Sharing opportunities to be involved • Asking people for ideas and support to share and disseminate what you want to tell people • Ask for feedback about how you are sharing information and attempt to measure the impact.

Resource 7: Answering important questions using Maslow's 'hierarchy of needs'

Maslow's hierarchy claims that needs that are **low** in the hierarchy must be partially satisfied before needs that are **high** in the hierarchy can be prioritised. Think of a hierarchy as a pyramid, 'low' meaning a basic foundation.

The answers to the questions on the left lie at the very heart of good meetings. They've been placed in an order to approximate to the hierarchy. Discuss whether you agree with the questions being placed with the associated needs?



Questions adapted from Roberta's Rules of Order by Alice Collier Cochran Published by 2004.

Resource 8: Patient, consumer and public involvement

There are many things to think about when involving the public and patients in improving services – this document is intended to help ask the right questions for the right roles.

How to use this resource: Under ‘Assumptions and barriers’, read the questions and consider if these might be barriers to involving some people, and consider how you might overcome these. ‘Learning needs and support’ examines the role in more detail and asks questions about the support people might need support to develop.

Be clear what you want– do you want ‘patient’, ‘user’ or ‘carer’ involvement, a lay perspective or just anyone who can give their time? Consider who you might unintentionally exclude by using these terms and be clear what you mean by *engagement* or *involvement*.

Assumptions and barriers	Role Description	Learning needs & support
<ul style="list-style-type: none"> What commitment do you expect (time/financial implications) Have you asked people to think about their emotional readiness? Do you expect them to be reading and writing information and documents? Have you considered what formats might be appropriate? Are you assuming a good ability to speak and read English? Do you expect a certain educational background? 	<p>Consumer/Lay Leader: A person who speaks and acts on behalf of all members of the public, including patients and carers and who takes a leading role in representing other lay representatives. The role may involve holding people or organisations to account.</p> <p>Consumer/Lay representative: a member of the public (not a professional) who is a representative. They must speak and act on behalf of others. They may be guided by lay leaders but will be expected to take direct action to ensure that they are informed and able to represent the views of others.</p>	<p>How are they supported to be a representative?</p> <ul style="list-style-type: none"> How will they be gathering views? Will this involve research? Do they have a budget? Should they be paid? Is there admin and practical support (from an organisation?) Is there any training available? <p>Who is already doing this?</p> <ul style="list-style-type: none"> Are there any opportunities for them to be involved in peer support or have or be a buddy? What can be shared with other organisations? (E.g. learning, resources) <p>How are people involved?</p> <ul style="list-style-type: none"> Can people be involved in other ways? (e.g. is it face to face meetings? What can be done online, what cannot?)
<ul style="list-style-type: none"> Are the people who have engaged with you the only people who might be interested? 	<p>Interested and engaged consumers or members of the public: People who know about and/or are interested in decisions being made, but may take no direct action other than giving feedback, being involved in a public dialogue or signing petitions.</p>	<p>Could there be a need for translation?</p> <ul style="list-style-type: none"> Are there any groups or organisations who could support with this? <p>Remember: ‘public dialogue’ is not fully ‘representative’ but can give a strong indication of how the public at large feels</p>
<ul style="list-style-type: none"> It is easy to assume that people who are not engaged don’t want to be. Often they won’t even know how they can contribute or be involved Some may not be able to afford the time, caring responsibilities or travel. 	<p>Uninformed, disengaged or disinterested members of the public: people who, for what ever reason, are not engaged, informed or interested in influencing decision making or shaping the future of health and social services.</p>	<p>A majority of the population are in this category.</p> <ul style="list-style-type: none"> What information or support might some people need to help engage them or move them into other roles? What might make people move back into this role? (e.g. not seeing direct improvements, or too much of organisational change?)

Remember: roles are not always fixed, they are often just a way of articulating different things people can or should do. Tasks can be more focused. There is always a way for dedicated people to give their time and develop their skills, what ever the label or role description

Resource 9: Questions to ask about research

Questioning everything is at the root of scientific understanding, that's what gives us knowledge. Good research attempts to answer questions using a rigorous method to give results.

Critical appraisal is a way of looking at published or reported research and asking questions about the validity of the methods, the results and how published findings can be acted on.

Below are some basic questions to ask of any research before it moves on from the design stage. When answering these questions, try to start with what is good, and then move onto what could be improved.

Ethics – Are the participants being recruited in an acceptable way? Is it possible to have informed consent? Are participants paid and is this relevant? Are participants exposed to unnecessary risk? Are the exclusion criteria appropriate or too excessive? (e.g. gender, age or being pregnant are common exclusion criteria)

Need – Does the research question address something of importance to the public and patients? Does it look at clinical need or an uncertainty about current treatment or services?

Public involvement – Do you think the public and consumers have been involved in identifying the need for the research, the design of this research or any other stages? Is there any budget for public and consumer involvement? Is there any evidence of public involvement?

Research method – is the research question clear? Is the method valid? Do you need more information to answer these questions? Is the research new or has it been done before (e.g. has a systematic review been done)?

Translation – is it clear how this research could be useful? If not, how could it be better explained?

Research Funding – Who is paying for this research, is there a conflict of interest? Is the cost of this research justifiable when compared with other priorities? Who owns the findings, data and the ults (e.g. intellectual property)?

Dissemination - Will the results and data be published? Will this be publicly accessible? (this may help avoid research being repeated). Will any of the successes of involving the public be shared?

The questions below can be more helpful to ask for clinical research:

Patient experience – what issues might there be? Will this potentially improve the experience of future patients?

Information – How is information presented to potential participants? What is good, what could be improved? Does this affect ability to give informed consent? Are the risks and benefits clear? Is the timescale and commitment clear?

For more detailed information on critical appraisal, find some free resources from the Critical Appraisal Skills Programme at:

<http://www.casp-uk.net>

Resource 10: Stories and facts about public involvement in research

All these stories are real but have been anonymised. Think about what these stories might mean and what you might learn from them. Please feel free to use them and add to the collection.

Why we involve the public – A researcher who spent his life researching arthritis was diagnosed with it towards the end of his career. He stated he'd spent his life researching the wrong thing. He was researching a cure when he should have been researching how to open jars. He should have been researching how to live with arthritis. The MS Society famously asked their supporters how they should spend their research budget and as a result they shifted their funding focus to curing and living with, rather than just curing.

Public involvement in participant information is an ethical issue

A 'Participant Information Sheet' (PIS) which had been through 'user testing' (involving the public to provide a lay perspective and improve it) produced a 'revised PIS significantly altered in its wording and layout'. This was compared with one that hadn't been revised. When given a written test, 66% of participants who read the revised PIS were able to show understanding of all aspects of the trial, compared with 15% of those reading the original version. Therefore the original PIS 'may not have enabled valid consent'.³²

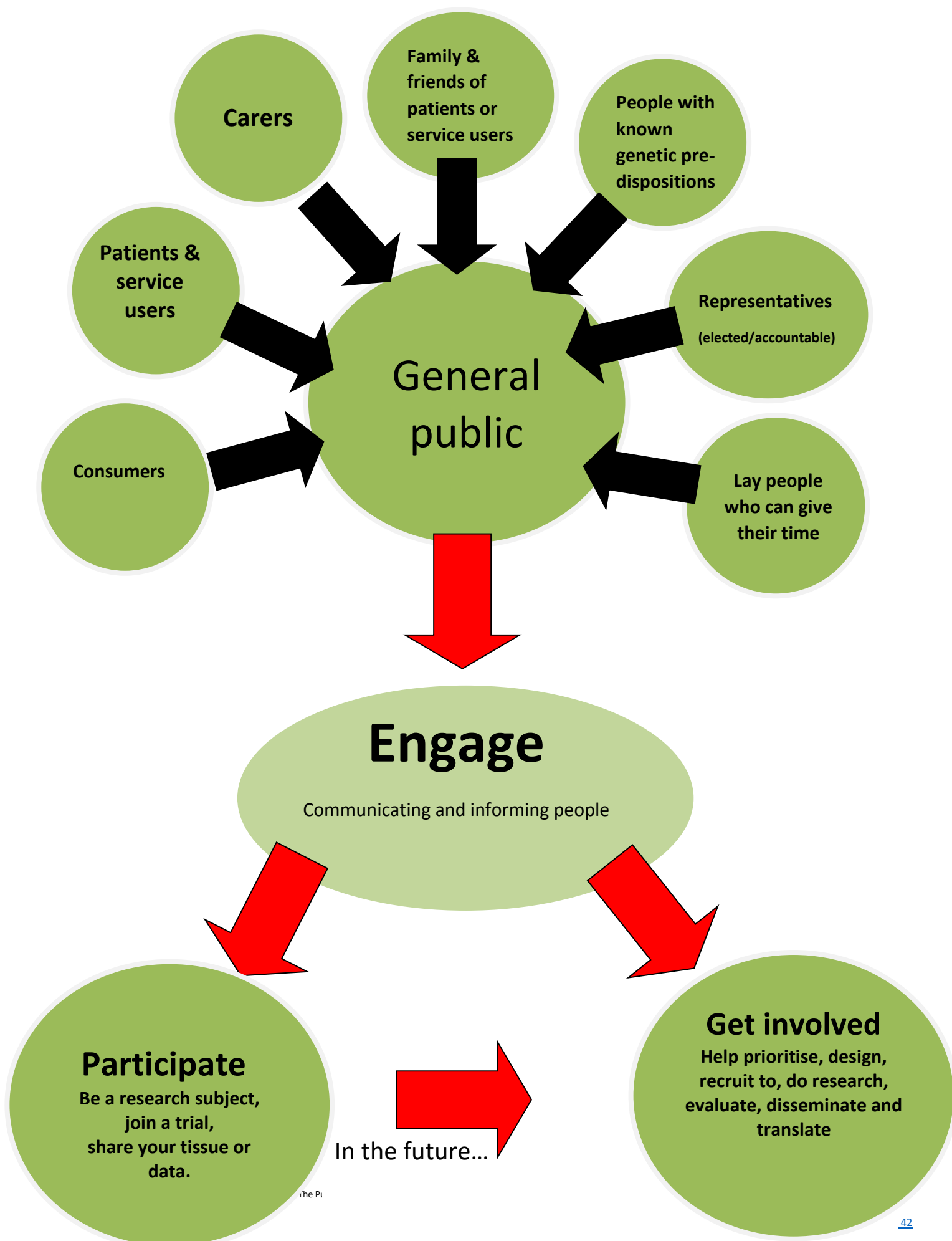
All information needs to be as clear as possible – A man's 2 year old daughter was in intensive care with advanced leukemia, doctors said she had a number of hours to live. While by his daughter's bedside, he was asked if he could leave the room for a moment and have a conversation. He was met by three doctors who sat him down at a table, all three on the opposite side to him. They wanted to recruit his daughter onto a clinical trial. He had to decide then and there if he would consent. He decided not to, because it felt too rushed. His daughter is now ten and doing well.

The public will be involved, one way or the other – A researcher who was leading a clinical trial into gene therapy on the back of the retina. While carrying out the trial, participants formed their own user group with no formal encouragement or financial support from professionals involved in the trial. They then began to give feedback to the trial organisers on how it was run and ways to improve it. This included changing the time of morning blood test appointments from 9am to 11am, as participants could then use their free bus pass. The result was that the trial retained many more participants, as the feedback made it more appealing to people involved. The researcher leading the trial was asked if they had written about the public involvement in their write up of the results. They said they hadn't, despite the fact it immeasurably improved the trial and quality of the results.

Know your audience - A Clinical Research Nurse based in Glasgow was doing quick study to work out how accessible local memory service appointments were for a individual living with dementia and their carers. The idea was to call the carer and ask them a few questions on the phone to help inform decisions on access. All the people being phoned had agreed to share their views for the study, but when the Nurse and her team set out to make the calls one afternoon, they noticed nobody was answering the phone, so they gave up. The next morning, everyone answered, and when they enquired as to why their calls had gone unanswered the afternoon before, a very common answer was "oh the news was on, so we don't answer the phone during that".

³² Reference Knapp et al. BMC Medicine 2011, 9:89 <http://www.biomedcentral.com/1741-7015/9/89>

Resource 11: Diagram of engagement, participation and involvement in research



Resource 12: The 6Rs

When working with others in a group or on a project, it can be helpful to make sure the following are as clear as possible:

Remit

- What is the purpose of the meeting/group?
- Are there any terms of reference? Does everyone have a copy?
- When they were last revised? Are they updated regularly?

Role

- Is each member clear about why they are there?
- What are people's expectations of you?
- Do you or others ever find that you have conflicting roles?
- What do others expect of you?

Representative

- Are you seen as a representative?
- If so, who are you supposed to represent? Do you have a constituency, a group of people whose views you aim to represent?
- How are you supported to be a representative? How might you gather people's views? How do you report back to them?
- Are you there because of a personal experience?

Responsibility

- What responsibilities do you or others have? (see terms of reference)
- Who sets the agenda? Is this responsibility shared?
- How are decisions made? How are they implemented? Who takes responsibility for reporting back and ensuring the wishes of the group are carried out?

Relationships

- Does it feel like being part of a team, everyone working together?
- Is there a sense of common purpose and goals?
- Do you get along with each other? Do you know each other as individuals or are you strangers brought together by your roles?

Readiness

- Are you ready to get involved? Have you considered your emotional readiness and any time commitments?
- Have you received any training to help you prepare for your role? Have you thought about how can you maintain and support your wellbeing?
- Do you know who or where you can go to for support regarding any of these issues?

Resource 13: Action plan

Use this resource to help you decide and plan what actions you might take.

What I would like to achieve is...

The next action I should take to achieve this is...

The result of this action might be...

Some other actions I can take to achieve this are...

I can get support from...

Some challenges I might face could be...

I could overcome these challenges by...

By this date_____ I will have...

Fill out swap sheet and tear and share. **Name:**

By this date_____ I will have:

Contact me by (e.g email):

Resource 14: Match the definitions to the letters

Action research



Systematic reviews



**Randomised
controlled trial**



**A case control
study**



**Translational
research**



**Qualitative
research**



**Laboratory
research**



A cohort study



Resource 15: Research Definitions

A. Research done in an environment (a laboratory) in which the team are able control and simulate clinical conditions or situations.

This research may include animal experiments or computer modelling.

B. Research that seeks to understand the experiences that people have in their lives. It captures knowledge that cannot always be counted in numbers.

It may be conducted by interviewing or observing people, using questionnaires or by reviewing case notes or diaries.

C. The researcher gains information about a particular problem or situation with the assistance of those who participate in the research.

It looks for solutions by carrying out 'an action' which is then reviewed to see whether it has addressed the problem. The process will be repeated until a satisfactory solution is found.

D. Research that studies a group of people who are free from disease but have been exposed to a potential cause of that disease.

These people may be compared with a control group that is similar but has not been exposed to the potential causal factor/s. Groups are followed up into the future to see what happens.

E. Research in which participants are randomly allotted or assigned to one of two groups.

One is the research group receiving an intervention, and the other is the control group receiving conventional treatment, no treatment or a placebo. Participants in both groups are monitored to see if any differences emerge.

F. Research that studies a group of people with a particular disease (an outcome of interest).

Researchers look back in time to see what those people may have been exposed to in order to identify possible causes of the disease. This is compared with a suitably matched but unaffected group.

G. A review of all the research studies that have been conducted into a particular topic where they have been systematically identified, appraised and then the results summarised according to pre-determined criteria.

This is usually carried out with randomised controlled trials but could also be used with other types of research studies.

H. A term used to define

research to test new treatments and diagnostic procedures for all diseases.

Research begins in the laboratory and covers all stages of experimentation up to and including transfer to 'first in human' clinical testing. Sometimes known as "from the bench to the bedside"

Resource 16: Different types of research methods

A Lab research: the researcher has total control over the environment and what happens to the sample.

B. Qualitative Research: Is the room warm enough?, each of you will have a different answer depending on how you feel and if asked to judge it from 1 to 10 will probably have a range of answers.

C. Action Research: when the water was contaminated in a reservoir the scientists needed to work out how to destroy the bug and make the water safe again so they tried various ways of treating the water e.g. did that work, yes/no, why, try this, what did that do, try this, etc.

D. Cohort Study (forward arrow) the Chernobyl radiation leak. Those exposed to radiation have been monitored to see the effects alongside another similar group not exposed. The study is to see what are the effects of the exposure compared to the control group.

E. Randomised Control Trial: two groups of people, of a similar mix of age, sex, disease etc are compared when testing a new treatment on one group against the current treatment on the other. Randomization allows the results to be as impartial as possible. Most clinical trials are Randomised Controlled Trials (RCT's).

F. Case Control Study: a group of young asthma sufferers were investigated to see if living in a damp house affected/caused the asthma. Scientists looked back at the life of each child to see if they could identify similar conditions that would help them find a cause that matched most/all of them.

G. Systematic Review: Systematic reviews compare all relevant randomised controlled trials in health care or all comparable kinds of research. For example, in 1993 the Cochrane Collaboration led a review that compared similar research that had been done around the world to determine how effective giving steroids to premature babies was as all previous trials had been inconclusive. The review compared all similar trials and concluded steroids saved lives.

H. Translational research: Also known as “from the bench to the bedside” this describes the process of designing/discovering a treatment in a laboratory and then the process it goes through till it is tested on humans in clinical trials. You “translate an idea into an action”.

Love drinking?

Hate the morning after?

If the answer is 'yes' and you are a healthy, 14-95 year old, and do not suffer from hay fever or chronic diarrhoea **then you could help us!**

Get paid to drink as much as you can!

No hangover!

You'll help us prove we've found a **miracle cure that banishes hangovers!**

If you complete our trial* **we'll pay you** compensation of up to

£2000**

*Further trial information available on request ** Upon signing our full disclaimer document and buying our recognised insurance policy*** ** Insurance costs **only** £700 a year

Resource 18: 'Participant Information Sheet – Phase II clinical trial'

HEPATIC – Participant Information Sheet – Phase II clinical trial

About the trial

The initial part of the trial will involve a 3-day 'party'. That's right!

We're inviting you to join us for an 'all you can drink' all expenses paid 3-day 'party'*.

What is it?

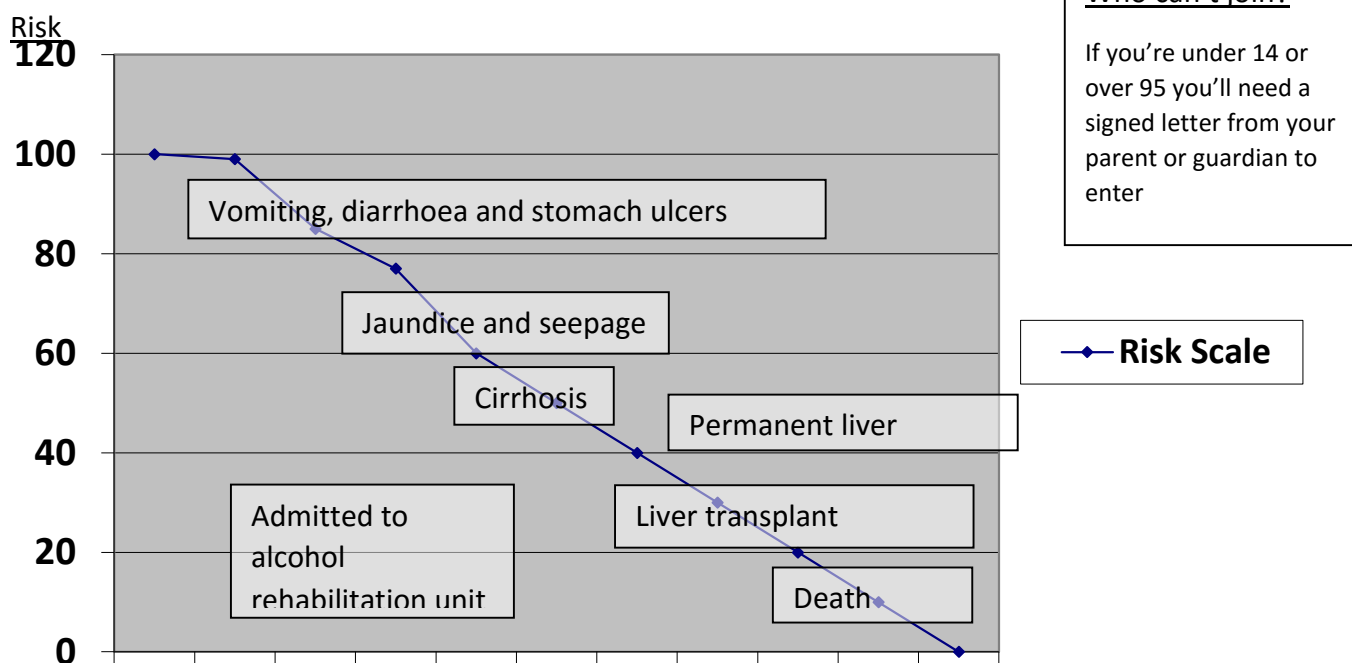
Hyper-enzyme polymerase action transmission inhibitor co-enzyme (HEPATIC) works by targeting the pathways in the multi-perplexion Maltbarely pathway. After ingestion into the alimentary canal, release through the hepatic portal vein transmits HEPATIC to the endocrine system, targeting the B52 receptors found on the Pilsner cells in the Laphroaig region of the liver. The HEPATIC compound works by inhibiting the active site of the hangoverase enzyme, which produces throb-clusters which enter the blood and attach to the gag-receptors in the brain and the back of the retina (further information on page 212). By inhibiting this enzyme, HEPATIC works by preventing the symptoms of hangover at the source.

More information about the trial

This phase 2 trial will take three years and involve 18 visits to your local trial centre. The centres are in Gunbalanya (West Arnhem Shire), Alice Springs and King Island, Tasmania. Each visit will require 2 pints of blood, a presentation of a week's worth of stool samples and 8 pints of urine (presented in a vessel of your choice). This research is being paid for by the Brewers Research Institute (BRI). The Brewers Research Institute is a company owned by the 'Teenage Alcopop Production Company'.

Pay

You will be paid after attending all 18 visits to your local trial centre. Please note that you can leave the trial at any point you like but you will not be paid and will be asked to contribute toward the cost of the drinks you have consumed.



*Please note that the word 'party' in this document refers to a controlled alcohol intake session, where participants will be given 4 units intravenously every 2 hours for a 48 hour period in isolation. Participants will be actively observed over

Additional resources

- Cancer Australia's [Consumer Learning](#) website comprises 23 learning modules to assist consumers to participate in research.
- Cancer Australia's [Consumer Involvement Toolkit](#) comprises over 90 resources to assist organisations and consumer to actively engage consumers in a shared focus and vision. Resources include videos, and testimonials from experts in their field, consumers, CEO's, researchers, policy makers and health professionals, along with practical tools.
- [Here](#) is a list of evidence compiled by Cancer Australia which supports consumer involvement.

Other pages of interest from Cancer Australia include:

- Why involve consumers? A resource for researchers:
<https://consumerinvolvement.canceraustralia.gov.au/researchers>
- Ways to involve consumers: <https://consumerinvolvement.canceraustralia.gov.au/researchers/ways-to-involve>

A selection of tools from Cancer Australia:

- <https://consumerinvolvement.canceraustralia.gov.au/tools>
- [Areas of research and kinds of involvement](#)